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Rehabilitating Ourselves: The Psychiatric Survivor Movement

My task, a very difficult one, is to present the views of users of psychiatric services with respect to psychiatric rehabilitation. Organizations of former patients/psychiatric survivors/mental health clients/consumers exist throughout the United States and in many other countries around the world—no one person can represent them all. And note the multiplicity of terms: there is no single term we are all comfortable with. I prefer to call myself a psychiatric survivor; my organization is the U.S. National Association of Psychiatric Survivors.

When I first became involved, twenty years ago, in what we then called the mental patients' liberation movement, we saw very clearly that what we were organizing was a civil rights movement. We were an oppressed group—oppressed by laws and public attitudes, relegated to legalized second-class citizenship. In the early 1970s, our movement was small and unfunded. People joined because they wanted a voice, because they saw coming together and organizing as a way to fight back against a system that had taken away their power and their control over their own lives. It was only with other former patients that we could express our anger, our pain, our outrage, without being dismissed as "delusional" or "paranoid." Although much has changed in twenty years, the basic fact remains that we are still oppressed, and that our movement is primarily a political one, a struggle for our rights.

Our movement is, at the same time, developing innovative self-

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help/mutual support alternative services, because we have learned, through having undergone similar experiences, that we have much to give one another. We are not afraid of one another's pain. Whereas mental health professionals often want to drug our pain out of existence, or isolate us so that they will not have to deal with that pain, we know how to offer comfort based on shared experience. It is simply a matter of common sense (but so much of psychiatric practice seems to be the antithesis of common sense) that when we are hurting, we want human contact, we want to know that we are not alone, we want comfort and caring. As peers, we can offer this support, knowing that although we may be the ones giving help today, tomorrow we may need that help, and the people we comfort today may then be our comforters.

Twenty-five years ago, I was diagnosed as a chronic schizophrenic. I was told what a limited life I could expect to lead. I originally entered a mental hospital voluntarily, seeking help for the overwhelming pain of depression that had followed a miscarriage. I expected to find help and understanding; instead, I found that no one listened to me or took me seriously. Heavy doses of psychiatric drugs were the "treatment." When I protested that I did not find them helpful, my opinions were simply dismissed. I soon found myself committed to a state hospital, where I remained for several months. It was the worst period of my life. My struggle to overcome the effects of this experience was what led me to become involved in an ex-patient group.

Our self-help/mutual support activities and our political activism are two aspects of the same endeavor, working together in our quest for decent lives. Our members distressingly often report the routine disrespect to which they are subjected in the psychiatric system: not being listened to, not being believed, infantilized, losing control of their own money, being told where to live, how to spend their time, being denied a normal sexual life—I could go on and on. These are not isolated complaints, but are an integral part of the operation of a system based on the presumption that mental illness equals incompetence equals the need for professionals to make decisions ostensibly "in our best interests."

In twenty years of organizing, I have personally spoken to literally thousands of current and former patients. I hear these stories again and again; and I also hear, over and over, the excitement and enthusiasm when people discover that there is a movement, that they can become a

part of it, and that we are articulating their interests. I have been fortunate in getting to travel; and wherever I go, all over the United States, in Canada, in Britain, in Iceland, in the Netherlands, in Italy, Portugal, Australia, or New Zealand, it is remarkable how similar the stories are, and how similar our organizations are. But, in fact, this is not really surprising. The psychiatric system is international, so our movement must be as well.

The key issue is forced treatment. This is something psychiatrists and other mental health professionals do not like to talk about, or else brush aside quickly, reassuring themselves that they are acting, reluctantly, "in our best interests," or claiming, disingenuously, that it is not organized psychiatry, but the state that administers involuntary commitment. But we who have been the recipients of involuntary commitment, of forced treatment, cannot brush it aside so lightly. We are the ones who, at a time in our lives when we were already feeling vulnerable, had whatever remained of our control, our decision-making power, taken away from us.

It is not surprising that this process makes us feel, quite accurately, even more powerless, even more out of control. Yet we learn quickly not to speak of our feelings. Talk about power, talk about being locked up, being in what to all intents and purposes is a prison, will only get us into more trouble, will get us further labeled. To be a good patient is to be grateful, to say, "Thank you, Doctor; I appreciate what you have done for me," while inside one's head a voice screams otherwise (and that voice is *not* a psychiatric symptom). To be a good patient is to learn to play the game, to lie convincingly, and, worst of all, to lie to ourselves until we no longer know what we believe.

When I talk to audiences of psychiatric survivors about playing the game, I see heads nodding, smiles of recognition—we *know* what it means to play the game: we have done it, we have lived it. And I should remind you, your patients also know how to play the game. You may want to believe that your hospital, your institution, your program is different, that you deal with your patients in a forthright manner; but so long as you work within a system based on coercion, patients and professionals are prevented from being honest with one another. If you do not believe me, I should say that it is you who are delusional.

So long as forced treatment exists, patients will continue to be angry, psychiatrists will continue to diagnose our anger as a symptom,

and we shall be stuck in the same tangle. And our movement is going to continue to organize around the issue of forced treatment, because it is the key issue from which all else flows. We simply cannot talk about working together for good treatment so long as we know that you have the power to determine that we will be treated whether we wish it or not. Professionals often want us to work together in partnership, but it is hard to be partners when there is such a huge and genuine power differential, especially when it is considered bad form even to point out that it exists.

If you want us to work in partnership with you, many things will have to change. You will have to open up the process so that we can enter into honest dialogue together. That means making it possible for us to attend your meetings and your conferences. And this process of inclusion must go far beyond conferences. We need to be involved in the planning, delivery, and evaluation of services. We need to be actively recruited into professional training and into professional positions. And we ask your support as we apply for funding for our own client-run alternative programs.

Good models exist. Mental health professionals should become familiar with our many successful client-run programs in the United States, and with models of user involvement in planning in Britain and the Netherlands.

As part of my work at the Center for Psychiatric Rehabilitation at Boston University, I am directing a study of the efficacy of client-run programs. In order to do meaningful research on self-help, program participants must be involved in a consultative, collaborative role, not be merely passive subjects of a research process controlled by others. In our study, an advisory board of twelve people involved in self-help programs by and for former psychiatric patients worked with me to figure out what were the important questions to ask about self-help, and professional researchers acted as consultants to help us put those questions into usable form. Participants in six different self-help programs around the United States were surveyed in terms of measures of self-esteem, friendship networks, empowerment, and satisfaction with participation in self-help programs.¹

The process of developing and administering client-directed needs assessments is in its infancy, but it is essential if services are to meet our self-defined needs. It is amazing how differently clients and professionals look at needs. Whereas professionals tend to take a purely

clinical view, we talk about far more basic needs: a decent place to live, an adequate income, friends, something productive to do with our time. We value programs that help us meet these needs; we do not think much of programs that continue to infantilize us, that continue to control our lives. People do participate in such programs, and they sometimes rate them well in client-evaluation studies; but often that is because they have little or no choice. If a program controls your money, for example, and your housing, and you know that your basic necessities depend on pleasing staff members, it is not surprising that, when asked, you will tell those same workers what a good program it is. And, I submit to you, this is how client satisfaction is measured in many, many programs.

Let me tell you about an alternative, client-run service, and how different it is. I shall use as a model the Ruby Rogers Center in Cambridge, Massachusetts,² which I helped to start. Our center is funded by the Massachusetts Department of Mental Health, but it is totally run and controlled by its members, all of whom have long-standing, ongoing involvement with traditional mental health services. In our center the basic decision-making is done by the members at our weekly business meeting. We decide how to allocate our funds, which members will get the paid jobs within the center, how to deal with people who break our rules, and how to keep our center comfortable and supportive. Our center is open seven days a week, and it is a place where members come to socialize, to see their friends, to participate in activities, to get information about the mental health system and about their rights, and to join together to work for better lives.

There are many centers like ours around the United States, and we are demonstrating that we can be effective in breaking the cycle of frequent rehospitalization and chronic difficulties in maintaining ourselves in the community. This is what we mean when we speak of client-run projects, *not* merely doing the menial work in programs run and directed by others.

Another client-run program is the Oakland Independence Support Center in Oakland, California. This is a program run by and for people who have been homeless and who have received psychiatric services. Although people with these two labels are often considered unable to help themselves and to need highly structured and supervised programs, the Oakland Independence Support Center has proven this not to be the case. The program works directly with homeless people,

helping them to get benefits, to find shelter, and, eventually, to move into decent, affordable, permanent housing. All the counselors have successfully made this transition themselves, and they are powerful role models for others.

Sue Estroff pointed out an important truth in her paper (see P. 88 of this journal), one we psychiatric survivors are well aware of, but one mental health professionals seldom, if ever, mention: the major thing we psychiatric patients produce is your jobs—and there are many well-paying, prestigious jobs among them. In contrast, many of us live on tiny disability pensions. How many mental health professionals appreciate how difficult it is to make a few hundred dollars last all month and give us credit for doing so month after month, year after year? Instead, we are frequently further diagnosed when we do not have enough money for rent or food, when we “squander” our money on a few simple pleasures, when we do not budget “properly.” And the solution, all too often, is for professionals to take control of our money, to dole it out a few dollars at a time, rather than join with us to demand that our benefits be raised to a decent, livable level.

So, again, in the end it all comes down to rights. We *could* say, “Let us learn how to live decently on our benefits” (as if that were possible); or we could, instead, struggle for a better benefit system, one that pays enough so we really could live decently, one that does not penalize us when we try to return to work. We *could* say, “Let us work to improve the existing services, even when they do not meet our needs”; or we could, instead, work to change the system so that it will provide the services we want, services we have a role in operating, and/or client-run alternative services. We *could* say, “Let us work for the right to decent treatment”; or we could, instead, work for all our rights as citizens, as human beings, including the right to refuse unwanted psychiatric interventions.

It is particularly important that we not settle for “rights” that are not rights at all. The first draft of the United Nations declaration on our rights spoke about the “rights of persons detained on grounds of mental ill health.” In the later draft, that language disappeared, and the document is now simply a listing of our “treatment rights.” I think we shall be worse off with this document than with no United Nations declaration at all, and I believe our movement will work to change this document and to ensure that we have a voice, our own voice, as part of the United Nations process to develop an appropriate document.

At the World Congress for Mental Health in Mexico City, the clients and survivors present (who constituted a very small number) laid the groundwork for the establishment of the World Federation of Psychiatric Users, with plans to circulate a newsletter internationally. In the Netherlands, a European Users' Network has been established, with delegates from most European countries and financial support from the European Community and the Dutch government.³ Linkages between groups in the USA and Canada are being strengthened, so we can speak with a united North American voice. And all this is being done with very little funding, out of our determination to work together on the issues that affect our lives.

In Burlington, Vermont, White Light Communications, a survivor-run video production business, is making and marketing videotapes about our movement. It is one of fourteen client-run programs around the United States originally funded as demonstration projects by the Community Support Program of the National Institute of Mental Health (NIMH).⁴ The NIMH has begun to involve ex-patients, survivors, and consumers in planning and evaluation meetings. In 1990 it sponsored a meeting on client views of alternatives to involuntary treatment. Sadly, NIMH has been criticized for this involvement, as if it were somehow improper for us to have any role at all other than being passive recipients of services. Despite these pressures, the Community Support Program has been a good friend of our movement, respecting our positions and recognizing that although we might not always agree, ours is a voice that deserves to be heard.

What does this all mean for psychiatric rehabilitation? I urge you to look at rehabilitation in its broadest sense. It is not merely that we are broken and need to be fixed. We exist in a society that is broken and that affects our functioning and our well-being. We are damaged by racism, by sexism, by classism, by heterosexism, by poverty and oppression. If our functioning is viewed in a vacuum, these factors are ignored, and we are seen as defective. If, instead, we are seen within the context of these factors, then efforts to help us will be much more meaningful and much less focused on our individual defects and pathologies. It makes little sense to ignore the society in which we all must live.

Rehabilitation, in its truest sense, must mean not only assisting our readaptation to society but recognizing the ways in which social practices prevent that readaptation. Stigma and discrimination must be hon-

estly faced and fought. Inadequate incomes and housing must be changed, or we can never live decent and comfortable lives. And unless the questions of power and powerlessness are dealt with in an open and frank way, we shall never be accorded our basic human dignity and our fundamental human and citizenship rights.

With or without the assistance of the mental health professions, we clients/consumers/ psychiatric survivors, in the USA and elsewhere, will define for ourselves what our needs are and what are the best ways for us to assume our rightful place in society.

Notes

1. The completed study showed that participants in self-help programs gained in all of these dimensions. Results of the study are currently (i.e., in 1995) in the process of analysis.
2. In 1994, the program moved to Somerville, MA.
3. The European Network of Users and Ex-Users in Mental Health held its second meeting in Helsingor, Denmark, in April 1994.
4. Now the Center for Mental Health Services.